



Complete Summary

GUIDELINE TITLE

NIH State-of-the-Science Conference Statement on improving end-of-life care.

BIBLIOGRAPHIC SOURCE(S)

NIH State-of-the-Science Conference Statement on improving end-of-life care.
NIH Consens State Sci Statements 2004 Dec 6-8;21(3):1-26. [PubMed](#)

GUIDELINE STATUS

This is the current release of the guideline.

COMPLETE SUMMARY CONTENT

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EVIDENCE SUPPORTING THE RECOMMENDATIONS
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SCOPE

DISEASE/CONDITION(S)

End-of-life conditions, including:

- Cancer
- Chronic heart failure
- Dementia

GUIDELINE CATEGORY

Management

CLINICAL SPECIALTY

Cardiology
Critical Care

Family Practice
Geriatrics
Internal Medicine
Nursing
Oncology
Psychiatry

INTENDED USERS

Advanced Practice Nurses
Allied Health Personnel
Health Care Providers
Nurses
Patients
Physician Assistants
Physicians
Utilization Management

GUIDELINE OBJECTIVE(S)

To provide health care providers, patients, and the general public with a responsible assessment of currently available data on improving end-of-life care

TARGET POPULATION

Patients dying of a life-limiting or chronic illness

INTERVENTIONS AND PRACTICES CONSIDERED

Management/End of Life Care

1. Defining the transition to end-of-life
2. Develop infrastructure and resources to enhance care
3. Effective communication among patients, families, and providers
4. Consideration of race, ethnicity, culture, gender, age and disease
5. Improved continuity of care

MAJOR OUTCOMES CONSIDERED

- Subgroup differences (disease, race, ethnicity, age, region, gender)
- Costs to patients, families, and health care systems
- Patient and caregiver satisfaction and distress
- Symptom management
- Spiritual well-being

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Note from the National Guideline Clearinghouse (NGC): A systematic review of the literature was prepared by the Southern California Evidence-based Practice Center for the Agency for Healthcare Research and Quality's Evidence-based Practice Centers Program for use by the National Institutes of Health (see the "Availability of Companion Documents" field).

A comprehensive search of the medical literature was conducted to identify studies addressing the key questions. Evidence-based Practice Center staff reviewed relevant articles, compiled tables of study characteristics and results, appraised the methodological quality of the controlled trials, and summarized results.

Sources for the review included MEDLINE®, the Cochrane Database of Reviews of Abstracts of Effects (DARE), the National Consensus Project for Quality Palliative Care, and several recent systematic reviews from both Health Canada and National Institute for Clinical Excellence (NICE), United Kingdom. The 2000 Toolkit of Instruments to Measure End of Life Care (TIME) was also used. Additional studies were identified primarily through searches by U.S. National Library of Medicine (NLM) staff, complemented by RAND library searches. The searches were limited to published articles in the English language, appearing in journals between the years 1990 through 2004, involving human subjects, and did not include individual case reports. NLM staff conducted the first search of PubMed® in April 2004.

At the title screening stage, citations that clearly met the following criteria were excluded: studies that enrolled only a pediatric population (age 18 years and under); those that were case studies with fewer than 30 cases; those that did not consider palliative care; those that enrolled a non Western population or were published in a non-English journal; reviews that were not systematic; clinical trials of chemotherapy, radiotherapy, stent, laser, endoscopy, or surgery (unless effects of the interventions were considered beyond effects on the primary disease process); descriptions of ethical, legal, or regulatory issues; descriptions of research processes; editorials, histories, personal narratives, and other descriptive non-clinical articles; articles about professional education (unless clinical or patient outcomes described); articles about organ transplantation or donation; articles that presented data only from prior to the mid 1980s; and studies in which the outcomes were lab or radiological tests or other physiological indicators. Approved titles moved on to the abstract screening phase.

Refer to the Chapter 2 in the Evidence Report (see the "Availability of Companion Documents" field) for further information.

NUMBER OF SOURCE DOCUMENTS

Systematic reviews: 95 articles

Intervention studies: 88 unique articles (109 entries)

Observational studies: 86 unique articles (93 entries)

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Weighting According to a Rating Scheme (Scheme Not Given)

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review of Published Meta-Analyses
Systematic Review with Evidence Tables

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Note from the National Guideline Clearinghouse (NGC): A systematic review of the literature was prepared by the Southern California Evidence-based Practice Center for the Agency for Healthcare Research and Quality's Evidence-based Practice Centers Program for use by the National Institutes of Health (see the "Availability of Companion Documents" field).

Implicit Quality Assessment of Systematic Reviews

Two reviewers reviewed all highly or possibly relevant systematic reviews or meta-analyses for quality independently. They then discussed their findings and reached consensus on the quality determination. No situations arose in which consensus could not be reached.

The reviewers categorized each review as either good, fair or poor quality. Good and fair reviews were acceptable to be used by the topic teams as evidence. The quality assessment was implicit. In this assessment the reviewers considered several characteristics of the review, drawing upon guidelines for assessing the quality of systematic reviews and meta-analyses. Good systematic reviews and meta-analyses met almost all of the standards below, and fair systematic reviews or meta-analyses met the majority:

- The search should be comprehensive, systematic and reproducible. Publication bias should be minimized, its existence assessed, and its possible impact on the conclusions discussed.
- The inclusion/exclusion criteria for studies should be clear, reproducible, and defensible, and a flowchart of studies should be provided.
- The study quality assessment criteria and process should be described and evidence-based.
- Data abstraction should be done by two independent readers with a consensus process, or by one reader after a reliability test.

- Individual study characteristics should be presented and possible causes for study heterogeneity considered and investigated.
- If the review is a meta-analysis, the pooling methods should be described and appropriate.
- The results of the review should follow from the evidence presented. Potential biases in the review process and their possible impact on the conclusions should be evaluated and discussed.

All systematic reviews assessed as good or fair quality were summarized by the topic area teams with a narrative description including an in-text table.

Assessment of Quality–Intervention and Observational Studies

To evaluate the quality of the individual intervention studies, Evidence-based Practice Center (EPC) staff collected information on the study design, withdrawal/dropout rate, method of random assignment (and blinding), and method for concealment of allocation (the attempt to prevent selection bias by concealing the assignment sequence prior to allocation) consistent with requirements for Office of Dietary Supplements (ODS)- Office of Medical Applications of Research (OMAR)-supported EPC evidence reports. The elements of design and execution (randomization, blinding, and withdrawals) have been aggregated into a summary score developed by Jadad. The Jadad score rates studies on a 0 to 5 scale, based on the answer to three questions:

- Was the study randomized?
- Was the study described as double-blind?
- Was there a description of withdrawals and dropouts?

One point is awarded for each "yes" answer, and no points are given for a "no" answer. Additional points are awarded if the randomization method and method of blinding were described and were appropriate. A point is deducted if the method is described but is not appropriate.

Observational studies were assessed using ODS-OMAR procedures. Because of the extremely large number of observational studies identified, EPC staff was forced to limit their review of observational studies by definitely accepting only those that met the following criteria consistent with the task order goals:

- If the study dealt with the topic of race/ethnicity as a single description of a racial group OR in the results reports racial differences, THEN it was included. If it did not do that AND it did not meet other criteria (b or c), then it was rejected.
- If the study dealt with a setting of care other than hospice or compared settings of care, then it was included. If it did not do that AND it did not meet other criteria (a or c) then it was rejected.
- If the study deals with the topic of congestive heart failure (CHF) or dementia it is included, OR if it dealt with a comparison of a non-cancer disease state with cancer, then it was included. If it did not do that AND it did not meet other criteria (a or b), then it was rejected.

Qualitative Data Analysis

The evidence is reported in several forms. First, the evidence tables (refer to Appendices E and L of the Evidence Report [see the "Availability of Companion Documents" field]) offer a detailed description of the studies that were identified, addressing each of the topic areas. At the end of the printed report, summary tables report on systematic reviews and intervention studies in an abbreviated form, using summary measures of the main outcomes. Narrative text summarizes the findings and provides qualitative analysis of the key questions as they relate to the topic area. The synergistic impact of multiple or sequential interventions is not considered with this methodology.

The evidence tables provide detailed information consistent with ODS-OMAR criteria about the study design, patient characteristics, inclusion and exclusion criteria, interventions evaluated, and the outcomes. The study sample size offers a measure of the weight of the evidence. (In general, larger studies provide a more precise estimate of the effect in question, although patient population governs more the applicability of any given study.) The evidence tables are condensed into in-text summary tables to provide a concise overview of study results. Summarizing the data in such a way allows for ease of comparison among studies.

Refer to Chapter 2 in the Evidence Report (see the "Availability of Companion Documents" field) for further information.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus (Consensus Development Conference)

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

To evaluate progress in the field of end-of-life care and clarify research priorities, the National Institute of Nursing Research (NINR), with the Agency for Healthcare Research and Quality (AHRQ), commissioned an evidence report as the basis for a State-of-the-Science Conference in December 2004. The National Institutes of Health (NIH) State-of-the-Science Conference on Improving End-of-Life Care was held on December 6–8, 2004, at the NIH in Bethesda, Maryland. The NINR and the Office of Medical Applications of Research of the NIH were the primary sponsors of this meeting. The Centers for Disease Control and Prevention, the Centers for Medicare & Medicaid Services, the National Cancer Institute, the National Center for Complementary and Alternative Medicine, the National Institute of Mental Health, and the National Institute on Aging were the cosponsors.

The AHRQ supported the NIH State-of-the-Science Conference on Improving End-of-Life Care through its Evidence-based Practice Center (EPC) program. Under contract to the AHRQ, the RAND Corporation and its partner, Veterans Administration Greater Los Angeles Healthcare System, developed the systematic review and analysis that served as important background for discussion at the conference.

A multidisciplinary Technical Expert Panel (TEP) was formed to assist the Southern California EPC with its review and to guide the evidence report. The TEP included

leading scientists and clinicians in nursing, gerontology, and palliative medicine, and others with a broad knowledge of relevant research and policy issues in both the United States and Europe. Research reviewers included an oncology nurse, an intensivist (a physician who specializes in the care of critically ill patients), a general internist, palliative care physicians, and gerontologists.

An impartial, independent panel was charged with reviewing the available published literature in advance of the conference, including a systematic literature review commissioned through the AHRQ.

Answering the Key Questions below, the non-Department of Health and Human Services, nonadvocate 10-member panel representing the fields of geriatrics, psychiatry, economics, health policy, nursing, philosophy, epidemiology, and oncology, drafted a statement based on scientific evidence presented in open forum and on the published scientific literature:

- What defines the transition to end of life?
- What outcome variables are important indicators of the quality of the end-of-life experience for the dying person and for the surviving loved ones?
- What patient, family, and health care system factors are associated with improved or worsened outcomes?
- What processes and interventions are associated with improved or worsened outcomes?
- What are the future research directions for improving end-of-life care?

The draft statement was read in its entirety on the final day of the conference and circulated to the audience for comment. The panel then met in executive session to consider the comments received, and released a revised statement later that day at <http://consensus.nih.gov>.

Refer to the original guideline document and Chapter 2 in the Evidence Report (see the "Availability of Companion Documents" field) for further information.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

The guideline developers reviewed published cost analyses.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Peer Review Process

Potential peer reviewers were identified through project staff, the Technical Expert Panel (TEP) and the Agency for Healthcare Research and Quality. Based on these inquiries 12 individuals with wide expertise in the field and with deep knowledge of the literature were contacted, 9 of whom provided recommendations in addition to the TEP members. Evidence-based Practice Center (EPC) staff selected reviewers because of their international stature, knowledge of both the North American and European literature, and research experience.

A copy of the draft evidence report was mailed to each peer reviewer and TEP member. All reviewers were asked to respond with their comments. The peer reviewer comments were compiled and appropriate changes to the draft report were made, based on these comments. The reviewer comments and the EPC's responses are provided in Appendix K of the Evidence Report (see the "Availability of Companion Documents" field).

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

Note: There is no exact definition of end of life; however, the evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death.

- Circumstances surrounding end of life are poorly understood, leaving many Americans to struggle through this life event.
- The dramatic increase in the number of older adults facing the need for end-of-life care warrants development of a research infrastructure and resources to enhance that care for patients and their families.
- Ambiguity surrounding the definition of end-of-life hinders the development of science, delivery of care, and communications between patients and providers.
- Current end-of-life care includes some untested interventions that need to be validated.
- Subgroups of race, ethnicity, culture, gender, age, and disease states experience end-of-life care differently, and these differences remain poorly understood.
- Valid measures exist for some aspects of end of life; however, measures have not been used consistently or validated in diverse settings or with diverse groups.
- End-of-life care is often fragmented among providers and provider settings, leading to a lack of continuity of care and impeding the ability to provide high-quality, interdisciplinary care.
- Enhanced communication among patients, families, and providers is crucial to high-quality end-of-life care.
- The design of the current Medicare hospice benefit limits the availability of the full range of interventions needed by many persons at the end of life.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is not specifically stated for each recommendation.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Improved quality of care provided to a dying individual and the surviving loved ones

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

QUALIFYING STATEMENTS

- The statement reflects the panel's assessment of medical knowledge available at the time the statement was written. Thus, it provides a "snapshot in time" of the state of knowledge on the conference topic. When reading the statement, keep in mind that new knowledge is inevitably accumulating through medical research.
- This statement is an independent report of the panel and is not a policy statement of the National Institutes of Health (NIH) or the Federal Government. A final copy of this statement is available, along with other recent conference statements, at the same web address of <http://consensus.nih.gov>.

IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

End of Life Care

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

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ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2004 Dec 6-8

GUIDELINE DEVELOPER(S)

National Institutes of Health (NIH) State-of-the-Science Panel - Independent Expert Panel

SOURCE(S) OF FUNDING

United States Government

GUIDELINE COMMITTEE

National Institutes of Health State-of-the-Science Panel

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

Panel Members: Margaret M. Heitkemper, Ph.D., R.N., F.A.A.N., (*Conference and Panel Chairperson*), Professor and Chair, Department of Biobehavioral Nursing and Health Systems Corbally Professor for Public Service, University of Washington, School of Nursing, Seattle, Washington; Deborah Watkins Bruner, Ph.D., R.N., Associate Member, Population Science and Radiation Oncology Director, Prostate Cancer Risk Assessment Program Director, Symptoms and Outcomes Research, Fox Chase Cancer Center, Cheltenham, Pennsylvania; Jerry C. Johnson, M.D., Chief, Division of Geriatric Medicine, Professor of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania; James O. Kahn, M.D., Professor of Medicine, University of California, San Francisco, Positive Health Program, San Francisco General Hospital, San Francisco, California; Mark S. Kamlet, Ph.D., Provost, Professor of Economics and Public Policy, Carnegie Mellon University, Pittsburgh, Pennsylvania; Jay Magaziner, Ph.D., M.S.Hyg., Professor and Director, Division of Gerontology, Department of Epidemiology and Preventive Medicine, University of Maryland, School of Medicine, Baltimore, Maryland; Heidi Malm,

Ph.D., Associate Professor of Bioethics, Department of Philosophy, Loyola University Chicago, Chicago, Illinois; Sharon McNeil, R.N., M.S., C.P.O.N., Clinical Nurse Specialist, Hematology/Oncology, All Children's Hospital, St. Petersburg, Florida; Judith A. Riggs, M.A., Senior Health Policy Advisor, Alzheimer's Association, Washington, DC; Jeanne Teresi, Ed.D., Ph.D., Senior Research Scientist, Columbia University, Stroud Center, Faculty of Medicine, New York State, Psychiatric Institute, Administrator and Director, Research Division, Hebrew Home for the Aged at Riverdale, New York, New York

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All of the panelists who participated in this conference and contributed to the writing of this statement were identified as having no financial or scientific conflict of interest, and all signed forms attesting to this fact.

Unlike the expert speakers who present scientific data at the conference, the individuals invited to participate on NIH Consensus and State-of-the-Science panels are reviewed prior to selection to assure that they are not proponents of an advocacy position with regard to the topic and are not identified with research that could be used to answer the conference questions.

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available from the [National Institutes of Health \(NIH\) Consensus Development Conference Program Web site](#).

Print copies: Available from the NIH Consensus Development Program Information Center, PO Box 2577, Kensington, MD 20891; Toll free phone (in U.S.), 1-888-NIH-CONSENSUS (1-888-644-2667); autofax (in U.S.), 1-888-NIH-CONSENSUS (1-888-644-2667); e-mail: consensus_statements@mail.nih.gov.

AVAILABILITY OF COMPANION DOCUMENTS

The following are available:

- NIH State-of-the-Science Conference on Improving End-of-Life Care. 2004 Dec. 102 p. Available in Portable Document Format (PDF) from the [National Institutes of Health \(NIH\) Consensus Development Conference Program Web site](#).
- End-of-life care and outcomes. 2004 Dec. Available from the [AHRQ Web site](#).

PATIENT RESOURCES

None available

NGC STATUS

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Date Modified: 3/23/2009

